



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

**Testimony of Jennifer Mathis
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On behalf of the Consortium for Citizens with Disabilities (CCD)**

**Before
Senate Committee on Health, Education, Labor and Pensions**

**EXAMINING HOW HEALTHY CHOICES CAN IMPROVE HEALTH OUTCOMES AND
REDUCE COSTS**

Oct. 19, 2017

Chairman Alexander, Ranking Member Murray, and Members of the Committee:

Thank you for inviting me to testify concerning this important issue. My name is Jennifer Mathis. I serve as Director of Policy and Legal Advocacy at the Bazelon Center for Mental Health Law, a national non-profit organization that works to promote equal opportunities for individuals with mental disabilities in all aspects of life through litigation, policy advocacy and public education. I am here also on behalf of the Consortium for Citizens with Disabilities (CCD), the largest coalition of national organizations working together to advocate for Federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.

Since the Committee's topic is broad, I will address employer-sponsored wellness programs as well as describing some ways in which broader health service delivery systems can and have promoted healthy choices that result in better health outcomes and reduced costs.

Workplace Wellness Programs May Hold Potential to Improve Health Outcome and Reduce Costs, but Must Not Erode Critical Workplace Protections for People with Disabilities

Employer-sponsored wellness programs have become increasingly prevalent as employers look for ways to reduce employee health care costs. According to the Kaiser Family Foundation, 90%

of large companies that offer health benefits offer some type of wellness program.¹ These programs may include health risk assessments and biometric screenings, as well as classes or other activities to help employees stop smoking, lose weight, or adopt healthier lifestyles or to manage chronic diseases such as diabetes.

While CCD believes that employer-based wellness programs have potential to promote individuals' health and well-being, we believe it is critical that such programs be administered in a way that does not undermine the workplace protections that Congress provided to employees with disabilities and their spouses in the Americans with Disabilities Act (ADA) and the Genetic Information Non-discrimination Act (GINA). These laws—both enacted with overwhelming bipartisan support—were adopted in response to a long history of workplace discrimination based on disability and on genetic information. They are important tools to help ensure fair workplaces for people with disabilities. In particular, they provide workplace privacy protections that enable people with disabilities to keep their health information private if it is not related to their ability to do their job, and to keep their spouses' health information private.

People with disabilities need these protections. The employment rate of people with disabilities has remained far lower than that of any other group tracked by the Bureau of Labor Statistics. Among working age adults, the employment rate of people with disabilities is less than half of that for people without disabilities.² This Committee has reported about the importance of efforts to improve this situation. In addition, the need to increase employment of people with disabilities has been a concern and a priority for federal agencies including the Department of Labor, the Department of Justice, the Department of Health and Human Services, the Equal Employment Opportunity Commission, and others. Against this backdrop, it is particularly important to ensure that employer-based wellness programs are implemented in ways that promote healthy behaviors *without eroding longstanding and critical workplace protections for people with disabilities*.

While the research over the last several years has consistently shown that the early assessments of workplace wellness programs' effectiveness in improving health outcomes and achieving cost savings appear to have been overblown,³ the primary concern of the disability community has

¹ Karen Pollitz & Matthew Rae, Henry J. Kaiser Family Foundation, *Changing Rules for Workplace Wellness programs: Implications for Sensitive Health Conditions*, at 2 (April 2017), <http://files.kff.org/attachment/Issue-Brief-Changing-Rules-for-Workplace-Wellness-Programs>.

² U.S. Department of Labor, Bureau of Labor Statistics, *Persons with a Disability: Labor Force Characteristics Summary* (June 21, 2017) (among persons age 16 to 64, the employment-population ratio in 2016 for people with disabilities was 27.7 percent, in contrast to 72.8 percent for people without disabilities), <https://www.bls.gov/news.release/disabl.nr0.htm>.

³ See, e.g., Soeren Mattke et al., RAND Health, *Workplace Wellness Programs Study: Final Report* (2013), <https://www.dol.gov/ebsa/pdf/workplacewellnessstudyfinal.pdf>; Soeren Mattke et al., RAND Corporation, *Workplace Wellness Programs Services Offered, Participation, and Incentives* (2014),

been the need for fair treatment by these programs. Whatever their utility, these programs should not punish people for having disabilities or pressure people to disclose sensitive health or disability information unrelated to their ability to do their jobs. The Affordable Care Act (ACA) and its implementing regulations provide some protection against wellness program incentives that punish people for having disabilities; where a program offers financial incentives to participants who meet a health standard or engage in an activity, the ACA requires that the program allow a person to meet a reasonable alternative standard if the person’s medical condition makes it “unreasonably difficult” or “medically inadvisable” to meet that health standard or engage in the activity.⁴

Concerns remain, however, about the use of wellness program incentives that are used to pressure employees to give up their rights to keep their own health information and their spouse’s health information private.

The ADA Requires Workplace Wellness Program Medical Inquiries and Exams to be Voluntary

The Americans with Disabilities Act (ADA) prohibits employers from subjecting employees to medical inquiries or exams that are not job-related and consistent with business necessity, unless they are “voluntary medical examinations, including voluntary medical histories, which are part of an employee health program available to employees at that work site.”⁵

The ADA’s medical inquiries provisions are part of a detailed scheme that Congress enacted to limit employer access to medical information from employees and applicants. Such limits are a core protection of the ADA. Due to the prevalence of negative attitudes about people with disabilities—including assumptions that they are not capable—Congress recognized that the best way to prevent discrimination was to ensure that employers simply did not have this information unless it was related to someone’s job performance. See S. Rep. 101-116, at 39-40 (1989) (“An inquiry or medical examination that is not job-related serves no legitimate employer purpose, but simply serves to stigmatize the person with a disability. . . . As was abundantly clear before the Committee, being identified as disabled often carries both blatant and subtle stigma. An

<https://www.dol.gov/sites/default/files/ebsa/researchers/analysis/health-and-welfare/WellnessStudyFinal.pdf>; Jill R. Horwitz et al., *Wellness Incentives In the Workplace: Cost Savings Through Cost Shifting to Unhealthy Workers*, 32 *Health Affairs* 468 (2013); Adrianno McIntyre et al., *The Dubious Empirical and Legal Foundations of Wellness Programs*, 27 *Health Matrix* 59 (2017).

⁴ 42 U.S.C. § 300gg-4(j)(3); 26 C.F.R. § 54.9802-1, §§ (f)(3)(iv), (f)(4)(iv). The ADA also requires that reasonable accommodations be provided, absent undue hardship, to enable employees with disabilities to earn whatever financial incentive an employer offers in a wellness program. The reasonable accommodation requirement will often be satisfied by the provision of a reasonable alternative or waiver of the standard or activity. 29 C.F.R. Part 1630 Appx., § 1630.14(d)(3): *Limitations on Incentives*.

⁵ 42 U.S.C. §§ 12112(d)(4)(A), (d)(4)(B). See also *EEOC Enforcement Guidance on Disability-Related Inquiries and Medical Examinations of Employees Under the Americans with Disabilities Act* (July 27, 2000) at Question 22, <http://www.eeoc.gov/policy/docs/guidance-inquiries.html> (“EEOC Guidance”).

employer’s legitimate needs will be met by allowing the medical inquiries and examinations which are job-related.”).

As the EEOC noted in its guidance concerning disability-related inquiries of employees:

Historically, many employers asked applicants and employees to provide information concerning their physical and/or mental condition. This information often was used to exclude and otherwise discriminate against individuals with disabilities -- particularly nonvisible disabilities, such as diabetes, epilepsy, heart disease, cancer, and mental illness -- despite their ability to perform the job. The ADA’s provisions concerning disability-related inquiries and medical examinations reflect Congress’s intent to protect the rights of applicants and employees to be assessed on merit alone, while protecting the rights of employers to ensure that individuals in the workplace can efficiently perform the essential functions of their jobs.⁶

For many years, the EEOC defined “voluntary” wellness program medical inquiries and examinations to mean that an employer may neither require participation nor penalize employees who do not participate.⁷ In 2016, however, the agency abandoned that interpretation and issued regulations providing that such inquiries and examinations are “voluntary” if the wellness program incentives for answering or participating do not exceed 30% of the cost of employee-only health insurance premiums. Such incentives would penalize employees who chose to exercise their privacy rights with penalties that could in many cases amount to thousands of dollars. At their maximum, these penalties would approximately double the amount that employees would have to pay for their health insurance. A federal judge has since concluded that the agency failed to provide any reasoned justification for or evidence supporting its new position.⁸

GINA Requires that Workplace Wellness Program Medical Inquiries of Employees’ Spouses be Voluntary

GINA provides similar protections barring employers from requesting, requiring or purchasing employees’ genetic information, including medical information of their spouses, with a similar exception for workplace wellness program requests that are voluntary. The EEOC’s

⁶ *EEOC Guidance*, General Principles.

⁷ *EEOC Guidance*, Question 22. While the guidance speaks of “voluntary wellness programs” rather than “voluntary medical inquiries” or “voluntary medical examinations,” it construes the ADA’s text relating to “voluntary medical examinations, including voluntary medical histories” that are part of an employee health program. It is clear that the guidance refers to penalties for answering questions or undergoing medical exams.

⁸ *AARP v. EEOC*, Case No. 1:16-cv-02113-JDB, Memorandum Opinion (D.D.C. Aug. 22, 2017).

implementing regulations define voluntary to mean that an employer may neither require employees to provide genetic information nor penalize employees who decline to provide it.⁹ When the EEOC changed its rules concerning the ADA's application to wellness programs, it also changed its rules concerning GINA's application, defining voluntary requests for the health information of an employee's spouse to allow financial incentives of up to 30% of the cost of employee-only health insurance premiums.¹⁰ These incentives would be *in addition* to any incentives for disclosure of the employee's health information, with the potential to create *astronomical increases in the cost of health insurance for families*. The same federal court that concluded that the agency failed to provide a reasoned justification or evidence supporting its new interpretation of "voluntary" under the ADA reached a similar conclusion about the agency's new interpretation of "voluntary" under GINA. The court remanded both rules to the agency, which must now revise its rules or provide appropriate support for them.

The EEOC now has an opportunity to revamp its regulations to ensure that employer efforts to promote employee wellness proceed without damaging the employment prospects of people with disabilities.

Penalizing the Exercise of Health Privacy Rights Damages the Employment Prospects of Workers with Disabilities

Such a "wellness-or-else" approach places significant pressures on many employees with disabilities to make unwanted disclosures of their health information, potentially putting their jobs at risk. Even though employers are not supposed to receive individually identifiable health information when a wellness program is run by a third party vendor, that protection offers little comfort to employees in employer-run programs, and to employees in small workplaces where it is not difficult to connect knowledge that someone has a particular disability with the employee in question. Furthermore, data breaches of sensitive information are not uncommon. Given the widespread attitudinal barriers that continue to hold people with disabilities back from securing, maintaining, and advancing in employment, extracting steep financial penalties for employees who exercise their right to keep health information confidential damages the employment prospects of people with disabilities.

Other Avenues to Improve Wellness Programs

We should be encouraging other means of improving wellness programs' effectiveness rather than encouraging steep financial penalties to try to force people to participate in wellness programs, including turning over sensitive health information. Notably, the principal author of

⁹ 29 C.F.R. § 1635.8(b)(2).

¹⁰ 29 C.F.R. § 1635.8(b)(2)(iii).

the federal government-sponsored RAND study—the lead study on wellness program effectiveness—stated:

Why do employees, and in particular those at high risk, choose not to participate? We do not yet have the evidence or insight to understand and convincingly answer that question. When we do, we will be able to design attractive and accessible programs. In the meantime, we should not penalize vulnerable employees who are reluctant to join marginally effective programs.¹¹

The RAND study, which included almost 600,000 employees at seven employers, found that well designed wellness programs succeed in promoting employee participation without the use of incentives. The study notes that comprehensive programs with genuine corporate and manager engagement in wellness, and commitment to monitoring and evaluating programs, tend to succeed. By contrast, limited programs, such as those that only use health risk assessments to glean information about employees' health, tend not to inspire participation without the use of incentive and tend not to reduce costs or improve health.¹²

The RAND study offered important guidance about factors that have demonstrated success in wellness programs. Those include, for example: clear communication about the goals of the particular wellness interventions being used, ensuring that the program's activities are convenient and easily accessible for all employees and consistent with their schedules, ensuring that the program's activities are aligned with employee preferences, soliciting ongoing feedback from employees, continuous evaluation of the program, strong support from leadership, and making full use of existing resources and relationships.

These strategies, rather than eviscerating important workplace privacy protections, should be the focus of wellness program development.

State Service Delivery Systems for People with Disabilities Can Expand Opportunities for Healthy Choices that Improve Health Outcomes and Reduce Costs

The Committee's examination of the impact of healthy choices on health outcomes and costs implicates many more areas than employer-based wellness programs, which play a relatively small role in this sphere. For example, state service systems have a critical role to play in enabling healthy choices that improve outcomes and reduce costs. The investments that states choose to make, and the manner in which they administer service delivery systems, have a significant impact on the available choices for people with disabilities to improve their health, and have significant potential to reduce health care costs.

¹¹ Soeren Mattke, When It Comes To the Value of Wellness, Ask About Fairness Not Just About Effectiveness, Health Affairs Blog (Mar. 18, 2015), <http://healthaffairs.org/blog/2015/03/18/when-it-comes-to-the-value-of-wellness-ask-about-fairness-not-just-about-effectiveness/>.

¹² Mattke 2013, *supra* note 3.

A key example of state strategies to promote healthy choices is the strategy of reallocating disability service system resources to decrease reliance on costly institutional services and expand home and community-based services, consistent with the ADA’s “integration mandate.” Expanding availability of key community-based services that enable people with significant disabilities to live in their own homes, participate in their communities, secure and maintain employment, and maintain health and well-being not only improves health outcomes but also significantly reduces costs.

This Committee has held a number of bipartisan hearings in recent years to explore the progress of states in implementing the ADA’s integration mandate. While those hearings demonstrated that we continue to have a long way to go in realigning service systems to promote independence and choice, they also underscored the importance of the shift toward community integration. The implementation of the integration mandate that has occurred in some states has demonstrated the improved health outcomes, improved life outcomes, and reduced costs realized through expanding community services and reallocating public service system dollars from costly institutional care to support people instead in their own homes and communities.

Below are examples of two states that achieved significant service system transformations as a result of their efforts to implement the integration mandate.

Delaware, through a settlement agreement entered with the U.S. Department of Justice, expanded core community services for people who received psychiatric inpatient care or emergency room care through public programs, who were homeless, or had a history of arrests or incarcerations. The development of this community capacity resulted in a decrease in the average census of the state psychiatric hospital by more than 55%—from 136 in Fiscal Year 2010 to 76 in 2016.¹³

In 2015, Delaware regularly diverted over 70 percent of individuals in crisis from acute psychiatric beds into less expensive community crisis services.¹⁴ Delaware also achieved a significant expansion in the number of people with serious mental illness receiving employment supports and working, quadrupling the percentage of individuals in the target population who were employed.¹⁵ Many thousands of individuals with serious mental illness have received needed community services and avoided institutionalization because of the service expansions and policy changes undertaken.

In New Jersey, an agreement between the state and the state protection and advocacy system, Disability Rights New Jersey, was reached in 2009 to develop community services for hundreds of people who remained institutionalized in state psychiatric hospitals even though they had been

¹³ Tenth Report of the Court Monitor on Progress Towards Compliance with the Agreement: U.S. v. State of Delaware, U.S. District Court for the District of Delaware, Civil Action No: 11-591-LPS (Sept. 19, 2016), https://www.ada.gov/olmstead/documents/de_10th_report.pdf.

¹⁴ *Id.*

¹⁵ *Id.*

determined to no longer need hospital care, due to the lack of community alternatives—as well as hundreds more who were at risk of admission to state psychiatric hospitals. New Jersey committed to provide these individuals with the services they need to live independent, integrated lives in the community.

The state developed 1436 new supported housing units for individuals waiting to be discharged from the state hospitals and for those at risk of admission to these facilities. It successfully discharged 294 of the 297 individuals who had been awaiting discharge for more than one year. In addition, New Jersey significantly reduced the length of time for which individuals remained hospitalized due to the lack of community services, ensuring more prompt discharges.

As a result of the increased access to supported housing and other services, New Jersey reduced admissions to psychiatric hospitals by one third between 2006 and 2010, a rate that has remained steady over subsequent years. In 2016, admissions had declined 36% from 2006 and the average daily census within state hospitals declined by 33.7%. The average daily census of the state psychiatric hospitals also shrunk by 34%, from 2,122 in 2006 to 1,406 in 2016.¹⁶

In addition, the number of individuals remaining in state psychiatric hospitals due to the lack of community options has shrunk by more than two-thirds since 2006. In 2006, these individuals comprised nearly half of all state hospital residents, whereas in 2016, they comprised only 22% of state hospital residents.¹⁷ The reduction in hospital beds has enabled the state to achieve a very significant expansion of community services. Over roughly the same period, the number of individuals served in the community has grown by almost 60,000 people.¹⁸ Supported housing is now the most common setting for individuals discharged from New Jersey's state psychiatric hospitals who need a place to live upon discharge.

¹⁶ New Jersey Dep't of Human Services, Division of Mental Health & Addiction Services, *Home to Recovery 2, 2017-2020, A Vision for the Next Three Years* (Jan. 2017), at 12, 13, <http://www.nj.gov/humanservices/dmhas/initiatives/olmstead/Home%20to%20Recovery%202%20Plan%20-%20January%202017.pdf>.

¹⁷ *Id.*

¹⁸ New Jersey Dep't of Human Services, Division of Mental Health & Addiction Services, *Realignment of the NJ Mental Health System* (powerpoint, July 1, 2015).